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ABSTRACT

Tourette Syndrome (TS) is described as a genetically based, chronic constellation of neurobehavioral symptoms and associated features involving repetitive, simple, and/or complex motor and phonic tics. Treatment generally involves neuroleptic medication. Symptoms of obsessive-compulsive disorder, attention deficit hyperactive disorder, learning disabilities, neuropsychological anomalies, school adjustment problems, and behavior or conduct disorders are often associated with Tourette Syndrome. Milestones unique to the course of Tourette Syndrome may include parents' realization that something is unusual about their child's behavior, a referral to a school psychologist, an official diagnosis, and subsequent parental involvement with a support group. The role of the school psychologist involves evaluation, case manager, counselor or therapist, and advocacy. School psychologists are in a unique position to be prime facilitators and advocates in promoting self-esteem, encouraging school achievement, and supporting warm family relationships and peer socializations. Appendices outline symptoms and frequency of behavioral difficulties. (Contains 23 references.) (JDD)

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TOURETTE SYNDROME AND ASSOCIATED FEATURES AND THE SCHOOL AGED CHILD

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syn.drome, *n. 1. Pathol., Psychiatry. a group of symptoms that together are characteristic of a specific condition, disease, or the like. 2. the pattern of symptoms that characterize or indicate a particular social condition.* (The Random House College Dictionary, 1973)

Tourette Syndrome (TS) is a genetically based, chronic constellation of neurobehavioral symptoms and associated features, originally described by Gilles de la Tourette in 1885. Prevalence is reported as at least 1:2000 (Cohen, et.al., 1985) or 1:1075 (Burd, 1986). An informal survey of four Rhode Island communities indicates a prevalence in the schools of 1:825. Comings and colleagues make the statement that approximately one in 100 individuals manifests one or more of the aspects of the TS gene (Comings, 1987c). Tourette Syndrome is more frequently reported in males than females by an approximate ratio of 3.4 to 1 (Woodrow, 1974).

The syndrome is diagnostically defined in terms of repetitive, simple and/or complex motor and phonic tics, which must occur for more than one year (DSM-III-R, 1987) (see Appendix A). The age of onset is before age 21, (commonly before age 10). Simple motor tics are sudden, brief, and appear meaningless (e.g. eyeblinking). Complex motor tics will be of longer duration, slower, and appear more purposeful (e.g. stretching the neck). Simple phonic tics are sudden meaningless noises or sounds (e.g. clearing the throat) while complex phonic tics are utterances that seem to carry more meaning (e.g. inserting an out-of-context word or phrase into conversation). (See Appendix B). Approximately 1/3 of patients with TS report difficulty with coprolalia, a complex vocal tic that involves the utterance of inappropriate or obscene words/phrases (Stefl, 1984). Many Tourette's patients learn to cover up tics, for example; they might repeatedly straighten a necktie to disguise a neck or shoulder tic.

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A hallmark of Tourette's Syndrome is the waxing and waning of symptoms. The frequency, intensity, type, and anatomical location of tics vary over the course of the disorder. Unfortunately, this often gives the mistaken impression that the patient "can help" the behaviors. The intensity of associated features is not always proportional to the frequency of phonic or motor tics. A child may exhibit very minor tics, yet have a great deal of difficulty inhibiting aggressive impulses. The frequency, intensity, and type of symptoms and associated features is also quite variable between individual patients.

Stress can exacerbate symptoms. Surwillo and his colleagues followed a 10 year old patient for 20 months, noting "major changes in symptom frequency ...associated with stressful life events such as the start of school and the beginning of little league baseball season" (Surwillo, et.al.,1978). Transitions (including the anticipation of transitions) are generally quite problematic for children with Tourette Syndrome.

TREATMENT

Neuroleptic medication (haloperidol, pimozide, fluphenazine, etc.) is generally the course of treatment for reducing the phonic and motor tics associated with TS. Unfortunately, there are several negative side effects to the use of haloperidol, including cognitive dulling, dysphoria or depression, irritability, violence, social withdrawal, school phobia or school avoidance, weight gain, and akathisia (Golden, 1990),(Bruun, 1988), (Weiden, 1987).

Clonidine is an alternative medication used to treat the tics of Tourette Syndrome. Mild side effects might include sedation or fatigue, dry mouth, faintness and/or dizziness, and irritability (Leckman, 1990).

Psycho-stimulant medication (methylphenidate), often thought as a precipitant to Tourettes, has been used in combination with haloperidol to treat TS patients with significant attention deficit disorders (Comings, 1987a).

Treatment for the psychological stressors and other associated features of Tourette Syndrome include antidepressant medication, psychotherapy, behavioral management, systems interventions, or a combination of approaches.

ASSOCIATED FEATURES

Symptoms of obsessive-compulsive disorder (OCD), attention deficit hyperactive disorder (ADHD), learning disabilities, neuropsychological anomalies, school adjustment problems, and behavior or conduct disorders are often associated with the more visible manifestations (tics) of Tourette Syndrome. Stressors generally associated with a chronic disease or handicap may be exaggerated in children with TS when they go for years with no diagnosis or misdiagnosis (Stefl, 1984). Social-emotional development in children with Tourette Syndrome is often delayed. Given the sometimes aggressive and socially inappropriate nature of Tourette symptoms, social discomfort/withdrawal and family conflict is often part of the syndrome.

Misunderstanding is arguably the most debilitating consequence of Tourette Syndrome.

OBSESSIVE COMPULSIVE DISORDER

Research indicates a prevalence of obsessive-compulsive symptoms in patients with Tourette Syndrome from 55% to 74% (Pitman, 1987), (Towbin, 1988) (Stefl, 1983). It is noteworthy that DSM-III excludes the diagnosis of obsessive-compulsive disorder if it is due to Tourette Syndrome. Towbin finds that obsessive compulsive symptoms "are considerably more prevalent among TS sufferers and their first-degree relatives than in the general population." (Towbin, 1988). He and others believe that Tourette Syndrome and Obsessive-Compulsive Disorder may (in many cases) be expressions of the same genetic etiology.

Obsessions are generally regarded as repetitive thoughts and compulsions as acts or behaviors. Obsessions in Tourette patients often involve forbidden sexual and aggressive images and impulses, worrying about blurting out an obscenity or doing something embarrassing, an over-awareness of bodily sensations, magical thinking, and a need for symmetry. Obsessions in OCD patients, without Tourette Syndrome tend to be more concerned with bodily wastes and secretions, dirt or germs, and contamination. Compulsions among Tourette patients tend toward self injurious behavior, compulsive touching, staring, urges to imitate others, and coprolalia. OCD (without TS) compulsions tend to be more in terms of cleaning and washing. (George, et.al., 1993) (Pitman, et.al., 1987).

The involuntary nature of Tourette related tics and/or compulsions is not universally seen. In one study, several subjects reported their compulsions as not outside their voluntary control,

while others denied any control (Pitman, et.al., 1987). However, George and his colleagues speculate that "in subjects with obsessive-compulsive disorder and Tourette's syndrome, the compulsion rises de novo, or before a conscious thought, and thus arises from a subcortical trigger, possibly from the basal ganglia or thalamus. For the subjects with obsessive-compulsive disorder, in which it is known that there is orbital-frontal hyperactivity, the stimulus starts as a cognition arising from the frontal lobe, which then triggers a compulsion." (George, et.al., 1993). Leckman and colleagues have observed that "premonitory urges are commonplace ... and that subjects ...frequently experience their movements as being a voluntary response to those unwanted urges." They go on to hypothesize that "Tourette's syndrome and etiologically related forms of obsessive-compulsive disorder are associated with a failure to inhibit subsets of the cortico-striato-thalamo-cortical minicircuits.(Leckman, et.al., 1993).

Obsessive compulsive symptoms in a school aged child with Tourette Syndrome presents a complicated picture in terms of classroom management and discipline. Direct confrontation of aggressive language or behavior can exacerbate the obsessiveness, dramatically worsening the situation. Telling a child with Tourette Syndrome to stop his misbehavior and watch his language may only heighten his anxiety, lessening his ability to get control of himself. It is also very unfair. A better approach might be to distract the child's focus from the aggressive ideation to more passive thoughts, perhaps an obsession that is less anxiety provoking. If the child must be removed from the classroom, in order to maintain order with the other children, a respite time in a non-punitive "safe-place," is recommended. Adults who supervise such a "safe" environment should respond to the child in a supportive, non-punitive, non-confrontational manner. The aggressiveness can be dealt with once the child is calm. Children with Tourette Syndrome should never be physically restrained, unless they are an immediate threat to their own safety or the physical safety of others.

ATTENTION DEFICIT HYPERACTIVE DISORDER

Attention deficit hyperactive disorder (ADHD) is reported in 25-35% (Golden, 1990), to 62% (Comings, 1987), of children with Tourette Syndrome. While it is true that psychostimulant medication (often used to treat ADHD) may bring on or exacerbate tics, it is incorrect to postulate that such medication may cause Tourette Syndrome.

Comings and his colleagues report that Tourette Syndrome "patients ...were significantly different from controls for DSM-III symptoms of inattention, impulsivity, and hyperactivity." (Comings, et.al., 1987a). They also take the position that cases of ADHD with a genetic link to Tourette Syndrome should be considered as a separate and distinct category from so-called "pure" ADHD.

SCHOOL PROBLEMS AND LEARNING DISABILITIES

The presence of attention deficit hyperactive disorder in a child with Tourette Syndrome is an important determinant of problems in school and the need for special education interventions. In one study, 46% of TS students with ADD were placed in a special class (EH, LH, SED) whereas only 17% of TS students without ADD were placed in a special class; 62.5% of ADD students without TS were in a special class (Comings, et.al., 1987a).

Difficulties with understanding language and the production of language are often associated with Tourette Syndrome. A speech and language evaluation should always be part of a complete diagnostic evaluation. 31% of TS patients in one study reported having difficulty with stuttering (Comings, et.al., 1987a). Other patterns of dysfunction relate to problems understanding what is heard and processing information into memory.

Poor retention of what is read is the most significant reading problem a student with Tourette Syndrome may encounter. Problems with retention may also interfere with social skill development. Bornstein and colleagues report Reading and Spelling scores on the WRAT (N=7) significantly better than the Arithmetic scores. They continue to say; "TS patients had difficulty with arithmetic only when visuomotor skills were required." (Bornstein, et.al., 1983).

Visuomotor impairment is also associated with Tourette Syndrome. Shapiro and colleagues report a high frequency of Bender-Gestalt records rated as impaired (Shapiro, et.al., 1974). The lowest scaled scores on the WISC-R in Bornstein's study were those regarded as measures of visuospatial organization (Block Design and Object Assembly). As a group, Bornstein's subjects performed in the average range for auditory attention span, but performed poorly on a test of visual attention span. (Bornstein, et.al., 1983).

Written language requirements may be too demanding for some students with TS. Accommodations for poor handwriting, taking notes in class, and written exams should be considered when developing an educational plan for a student with TS.

BEHAVIOR / CONDUCT DISORDER

Many features of Tourette Syndrome can be described in terms of disinhibition. Comings proposes that "the basic defect in TS may be a disinhibition or the limbic system" (Comings, 1987c), the anatomical mechanism that some have conceptualized as the system responsible for the regulation of emotion. Behavioral and conduct problems associated with Tourette Syndrome can be viewed as an effect of a failure of inhibition of aggression (Riddle, et.al., 1988). Aggressive acts (similar to tics and other associated behaviors) occur more frequently in an environment where the patient feels comfortable and is less concerned about embarrassment and/or retaliation. This explains why a child may control (to some degree) his tics and associated behaviors while at school, only to have his symptoms erupt when he gets home. Riddle and his colleagues continue to say that targets of a TS patient's aggressiveness are usually "selected" to minimize the possibility of retaliation, often pets or smaller children. (Riddle, et.al., 1988).

Compared to a control group, children with Tourette Syndrome show a significantly higher frequency of behavioral symptoms such as; extreme temper, inability to tolerate delay, temper tantrums, fighting, being destructive, being unresponsive to discipline, lying, stealing, aggressive behavior, fighting, vandalism, and the inability to accept correction (Comings, et.al., 1987b), (Stefl, 1984), (Stewart, et.al., 1981).

As is the case with school problems and learning disabilities, the presence of ADHD plays an important role in the incidence and severity of such behavioral difficulties in children with Tourette Syndrome. Generally speaking, the more severe the ADHD, the more severe the conduct problems (Comings, et.al., 1987c). However, conduct problems in TS patients without ADD were also significantly more frequent than a control population or ADD patients without TS.(Comings, et.al., 1987b).

Stefl reports (see Appendix C) that "Behavioral patterns often associated with pathology (extreme temper, aggression, hyperactivity, anxiety, obsessive compulsive behaviors, and mood swings) are reported in two-thirds to three-fourths of the respondents (in her study). Self-abusive behavior was a problem for one-third of the respondents. Coprolalia was reported a problem of some form by 36.3 per cent of the respondents.

"Aggressive behavior, hyperactivity, extreme temper, and bedwetting were uniformly more prevalent in males than females. Problems with coprolalia increased with age, but problems with bedwetting decreased." (Stefl, 1984).

The presence of obsessive compulsive disorder in a TS patient is a contributing factor to behavior/conduct problems, particularly in terms of lying and stealing. Depression is also a contributing factor.

STRESSORS ASSOCIATED WITH A CHRONIC HANDICAP/DISORDER

Denial, social isolation, and depression are psychological factors common to children suffering from a chronic disorder. A child with Tourette Syndrome may refuse to acknowledge the existence of the disorder, refusing to even say the words. When a child asks himself "Why me?" (as many sufferers of chronic diseases do), answers such as "because I'm bad," or "I'm stupid," or "because God hates me," are obvious assaults on his self esteem. Such issues must be not be left to fester into depression.

SOCIAL DISCOMFORT

Delays in social-emotional development are not uncommon in children with Tourette Syndrome, particularly if they have been isolated from the mainstream in a special education class. This social immaturity, coupled with social skill deficits can lead to a lack of social (self) confidence and social isolation. Stokes and colleagues report children with TS were rated by their peers as "more withdrawn" and "less popular". Children with ADHD in addition to Tourette's Syndrome were rated significantly "more aggressive." (Stokes, et.al., 1991).

MILESTONES

Parents of a child with Tourette's Syndrome encounter a series of milestones unique to the course of the syndrome. The first comes when they begin to realize that something is more than a little unusual about their child's behavior. Guilt, confusion, and embarrassment, confound a rising concern for their child's mental health. Subtle (and not-so-subtle) criticism from friends and family may cause them to question their parenting skills. The strain on the marriage can be immense.

The next milestone comes when the school psychologist or guidance counselor calls from school and says "Johnny is having a terrible time staying on task, and he keeps making these grunting noises." This is usually followed by several evaluations that may put "Johnny" into some variety of special education service, appropriate or otherwise. It is noteworthy that not all children

with Tourette's Syndrome will come to the attention of school personnel. Many manage to control their tics and associated behaviors well enough in school, only to "let it all out" in the comfort of their home.

The official diagnosis of Tourette's Syndrome is probably the most memorable milestone. Usually after any number of misdiagnoses, attaching the proper name to the constellation of tics, noises, and behaviors finally offers relief from the guilt, confusion, and embarrassment that may have been plaguing a family for several years. As parents begin to educate themselves, they soon learn that most people who interact with their child have very little or no understanding of TS. They become advocates, ...often a lonely role.

Another milestone comes when the parent attends a Tourette Syndrome support group. The realization that they are not alone in their trials and tribulations is usually quite comforting.

There are, of course, other milestones that follow the normal course of development, such as the birth of siblings, puberty and adolescence, separation and individuation, dating and marriage, to name a few. Milestones all colored by Tourettes, for better or worse.

THE ROLE OF THE SCHOOL PSYCHOLOGIST

As it is with many issues facing school psychologists, his/her role with a child with Tourette's Syndrome is multi-faceted.

The traditional role of evaluator and "gatekeeper" to special education is usually the first to befall the school psychologist. While many students with TS are squeezed into learning disabled, emotionally handicapped, or behavioral disordered classifications (justifiably in many cases), a more appropriate classification might be "other health impaired," (if indeed there is some impairment to the child's ability to learn). Students with Tourette's Syndrome and their parents also have certain rights under Section 504 of the Rehabilitation Act of 1973, regardless of how well the student performs in school.

Another role is consultant or case manager. School psychologists should be well versed in the symptoms, effects, and associated features of Tourette's Syndrome so as to provide competent consultation to teachers, administrators, employers, and parents. The far reaching impact of Tourettes should always be taken into account when planning special education interventions, regular classroom accommodations, alternative approaches to discipline, behavior management programs, and especially transition plans from grade to grade, school to school. Systems or

environmental interventions (e.g. peer training and family support) can often be orchestrated by the school psychologist.

Counselor or therapist is also an important role for school psychologists working with students with Tourette's Syndrome. General goals for counseling include helping the client adjust to the impact of the syndrome through various stages of development. The psychodynamics of the individual, the family, and the syndrome itself must be continually evaluated. Reactions common to chronic illness, such as depression, denial, and social isolation must not be overlooked. Issues of self esteem must be addressed. Given these issues, and the frequency of obsessions and compulsions, issues of adolescence, normally difficult for most, can seem insurmountable to a teenager with Tourette Syndrome. The guidance of a skilled therapist, with a knowledge of Tourettes is critical.

The primary role of the school psychologist is to advocate for all children. Children with Tourette's Syndrome have a special need for informed, professional advocacy, such as can be provided by school psychologists. Perhaps the most debilitating feature associated with Tourette's Syndrome is the lack of understanding or (worse yet) the superficial understanding of the syndrome and those afflicted. In misguided efforts to meet the educational needs of a child with Tourette's Syndrome school personnel occasionally try to tailor their peripheral understanding of TS into a more familiar, albeit loose-fitting, context of an educational classification (LD, EH, BD, etc). Physicians, who may be aware of the diagnostic criteria and pharmacologic interventions, may not have a full appreciation of the ramifications Tourette's Syndrome can have on learning, social-emotional development, and family dynamics. The role of parents, who are most often the "best informed" about their child's TS, is often minimized, either by intent or oversight. However, when a well informed parent is coupled with a concerned and knowledgeable professional like a school psychologist, it makes for an alliance of advocacy that is impossible to ignore.

Advocacy begins with understanding, which is the by-product of training and experience. School psychologists should develop a working knowledge of the symptoms and treatment of Tourette's Syndrome, the associated features, the effects on social, emotional, and educational development, and the overall impact the disorder can have on a child's family, school, and life experience. Material available from the Tourette's Syndrome Association and the references cited in this presentation are good places to begin. Direct experience working with a student with Tourette's Syndrome, his teachers, and family is a most valuable road to understanding as well.

Towbin and his colleagues offer the conclusion that "helping to keep the patients development on track - supporting warm family relationships and peer socializations, facilitating school achievement and rewarding employment, and promoting self esteem - appears of greater clinical value than mere suppression of tics at whatever cost." (Towbin, et.al., 1988). School psychologists are in a unique position to be a prime facilitator and advocate in this regard.

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RESOURCES

The following book is highly recommended as a resource to parents;

Children with Tourette Syndrome
A Parents' Guide
Edited by Tracy Haerle

Published by;
Woodbine House, 5615 Fishers Lane, Rockville MD 20852,(800)843-7323

A collection of brochures, videos, and articles are available from;

The Tourette Syndrome Association, Inc.
42-40 Bell Blvd
Bayside NY 11361
(718) 224-2999

Questions and requests for copies of this paper should be addressed to;

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APPENDIX A

DSM-III-R diagnostic Criteria for 307.23 Tourette's Disorder:

A. Both multiple motor and one or more vocal tics have been present at some time during the illness, although not necessarily concurrently.

B. The tics occur many times a day (usually in bouts), nearly every day or intermittently throughout a period of more than one year.

C. The anatomic location, number, frequency, complexity, and severity of the tics change over time.

D. Onset before age 21.

E. Occurrence not exclusively during Psychoactive Substance Intoxication or known central nervous system disease, such as Huntington's chorea or postviral encephalitis.

APPENDIX B

Symptoms:

Simple Motor Tics

Eye Blinking
Eye Movement
Facial Grimacing
Nose Twitching
Shoulder Shrug
Arm Jerk
Tongue Wagging / Fluttering
Neck Stretching
Facial Twitching
Head Jerking
Mouth Movement
Lip Pouting
Abdominal Tensing
Kicking
Finger Movement
Jaw Snapping
Tooth Clicking
Rapid Jerking of any part of body

Simple Phonic Tics

Throat Clearing
Tongue Clicking
Sniffing
Coughing
Spitting
Screeching
Barking
Grunting
Gurgling
Clacking
Sucking
Hissing
Other Inarticulate Sounds

Complex Motor Tics

Sustained Looks
Facial gestures
Biting
Touching objects or self
Touching other people
Throwing
Jumping
Banging
Thrusting Arms
Hand gestures
Gyrating, Twirling, and Bending
Dystonic Postures
Copropraxia (obscene gestures) Echokinesis (imitation of the movements of another person

Complex Phonic Tics

Coprolalia (Obscene / Inappropriate words / phrases)

Syllables, Words, Phrases out of Context

Echolalia (Repeat words of others)

Palilalia (Repeat one's own last words)

Stuttering

Unusual Speech Rhythm, Tone, Volume, Intensity, Accents

APPENDIX C

Frequency of Behavioral Difficulties Reported by Respondents (Percent responses)

Problem Area	Frequency		
	Often	Sometimes	Never
Extreme Temper	28.9	46.4	24.6
Obsessive-Compulsive Behavior	32.3	41.7	26.0
Hyperactive Behavior	29.2	43.8	27.1
Self Abusive Behavior	7.2	27.1	65.7
Extreme Anxiety	31.6	48.3	20.0
Extreme Mood Swings	32.7	42.8	25.5
Aggressive Behavior	24.8	39.2	36.0
Coprolalia	13.3	23.0	63.7
Running Away from Home	1.0	9.0	90.0
Lying and Stealing	14.1	32.3	53.6
Getting to Sleep	22.4	43.0	34.6
Staying Asleep	10.6	27.4	61.9
Sleepwalking	2.6	14.7	82.7
Bad Dreams; Night Terrors	9.5	40.0	50.5
Bedwetting	8.4	12.8	77.0
Loss of Bladder Control during Waking Hours	2.1	6.2	91.7

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